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ABSTRACT

This executive summary describes the movement of people with developmental disabilities toward the goals of independence, productivity, and integration, as evidenced by reports prepared by the State Developmental Disabilities Planning Councils. The summary outlines findings from state reports in relation to major life areas: learning; working; housing; health; civil rights; and related supports to individuals, families, and communities. The executive summary presents goals for people with developmental disabilities, recent accomplishments at the state and local level, quotes from consumers and family members, and recommendations directed primarily at the federal level. State surveys were conducted on the status of individuals with developmental disabilities and their satisfaction with services being received, and data are presented in the areas of independence, productivity, and integration and the major life areas. Critical issues and barriers are discussed, such as the availability of particular supports, services, or programs; their accessibility; their lack of focus on independence, productivity, and integration; the quality of services; and consumer control. Groups reported as unserved or underserved are listed. (JDD)

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VISIONS OF:

Independence • Productivity • Integration for people with developmental disabilities

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VISIONS OF:

Independence — Productivity — Integration

for People with Developmental Disabilities

A Summary of Reports Prepared by

State Developmental Disabilities Planning Councils

Executive Summary

U. S. Department of Health and Human Services
Office of Human Deveopment Services
Administration on Developmental Disabilities

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Acknowledgments

The Administration on Developmental Disabilities gratefully acknowledges:

Americans with Developmental Disabilities and tier Families for sharing their hopes, dreams and aspirations with us.

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Temple University for Outstanding Technical Assistance.

Tecla Jaskulski and Associates for creating a way to communicate the results.

and

The Creative and Dedicated People who will use this report to forge a future of independence, productivity and integration into the community for Americans with Developmental Disabilities.

Cover: Artwork reprinted by permission of the artist, Martha Perske, from *Circle of Friendship* by Robert Perske. (Nashville: Abington Press)
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Independence — Productivity — Integration

for People with Developmental Disabilities

Executive Summary

"We hold these Truths to be self-evident, that all Men are created equal, that they are endowed by the Creator with certain inalienable Rights, that among these are Life, Liberty, and the Pursuit of Happiness—"

—The Declaration of Independence in Congress, July 4, 1776

People with developmental disabilities are, as have other groups before them, slowly beginning to realize the American ideal of life, liberty, and the pursuit of happiness. As the United States progresses into the twenty-first century we are a maturing nation that is continuing to apply the truths of our forebears to new groups of people in our country. The summary that follows describes the movement of people with developmental disabilities toward the goals of independence, productivity, and integration, as seen through the reports recently prepared by the State Developmental Disabilities Planning Councils and submitted to the Secretary of the Department of Health and Human Services by the governors of the states and territories. The Executive Summary is about programs and changing priorities, but more than that, it is a tribute to the people behind these new priorities and programs—federal and state and local policymakers, service providers, families, friends and employers, and, most importantly, people with developmental disabilities themselves.

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The 1990 Summary Report to Congress and this Executive Summary represent the collective efforts of the Administration on Developmental Disabilities, 55 Developmental Disabilities Planning Councils, several University Affiliated Programs, national organizations, and many other individuals to respond to the legislative requirements of the Developmental Disabilities Assistance and Bill of Rights Act, as amended by P.L. 100 - 146.

The term *developmental disabilities* applies to people with a mental or physical impairment that was manifested before their twenty-second birthday, that is likely to continue for an indefinite length of time, and results in "substantial" functional limitations in at least three areas of major life activity. Although precise determinations of the size of the population of people with developmental disabilities are lacking, estimates range from two million to about three million people, nationwide. Developmental disabilities pose significant challenges for families and friends and especially for the individual with a developmental disability. It is to respond to these challenges that the Administration on Developmental Disabilities and its programs exist.

Requirements of P.L. 100–146

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (P.L. 100-146) required each State Developmental Disabilities Planning Council to conduct a comprehensive review and analysis of services for people with developmental disabilities as they affect their ability to achieve the goals of independence, productivity, and integration into the community. It further required them to survey people with developmental disabilities as to their satisfaction with these services. The Councils were then to convene public forums to provide the results of their analytic work and to obtain the comments and recommendations of the public.

The Administration on Developmental Disabilities supported extensive assistance to Councils in their responses to the requirements of P.L. 100–146, including broad-based technical assistance coordinated by the National Association of Developmental Disabilities Councils. A key component was the design and training in a common approach to the state consumer surveys, used by all but five of the Councils nationwide, and guidance on approaches to the policy analysis. At the state level, Council efforts to involve consumers included the direct input of over 15,000 individuals with developmental disabilities whose responses to the state consumer surveys, participation in public forums, and work on Council committees were essential to the development of the State Council reports. Consumer perspectives were synthesized in the reports with the results of each Council's analysis of the state agency administered programs that are supported by federal and state funds and which affect the lives of people with developmental disabilities.

Section 122(f)(4) of the Developmental Disabilities Act Amendments (P.L. 100–146) required the Councils to submit a report on the results of these activities to their governors and legislatures by January 1, 1990. Fifty-five reports have been submitted to the Secretary of Health and Human Services by the governors of the states and territories. This document is a summary of the fifty-three reports that were received in time for inclusion in the national summary.

The approach to preparation of the Summary Report was a careful review of the reports submitted by the governors of the states and territories. Findings from the State Planning Council reports were summarized in relation to major "life areas": learning (education), working (employment and income), housing, health, civil rights, and related supports to individuals, families and communities. Within each area, the 1990 Summary Report looks at the **goals** for people with developmental disabilities defined in the individual Council reports, as well as the descriptions of **recent accomplishments** at the state and local level. The reported perspectives of people with developmental disabilities and family members also have been used extensively in the preparation of the summary report. Altogether, over 3,100 statements of **issues and barriers** and approximately 3,200 **recommendations** were reviewed in summarizing the views of the Planning Councils of the states and territories. Supported by funds from the Administration on Developmental Disabilities, a compilation of findings from the reports prepared by the National Association of Developmental Disabilities Councils also was a major resource. A similar compilation of state consumer surveys, prepared by the Temple University Developmental Disabilities Center/University Affiliated Program for the National Association of Developmental Disabilities Councils, was the source of information on the surveys of consumers.

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The following graphic conventions to assist the reader are found throughout the executive summary:

Goal/vision statements

★ Accomplishments

❝ Quotes from consumers and family members

Recommendations directed primarily at the federal level

The recommendations and analyses contained in this report reflect the experience and opinions of the State Developmental Disabilities Planning councils and are not the official position of the Administration on Developmental Disabilities or the Secretary of Health and Human Services.

Goals for People with Developmental Disabilities

Federal Policy Goals

The Developmental Disabilities Assistance and Bill of Rights Act contains a clear vision statement for people with developmental disabilities:

The program goals for people with developmental disabilities contained in the Developmental Disabilities Assistance and Bill of Rights Act are—

...to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community, and

...to protect the legal and human rights of persons with developmental disabilities.

Independence

"The term 'independence' means the extent to which persons with developmental disabilities exert control and choice over their lives."

Productivity

"The term 'productivity' means—

"(A) engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or

"(B) engagement by a person with developmental disabilities in work which contributes to a household or community."

Integration into the Community

"The term 'integration' means--

"(A) the—

"(i) use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and

"(ii) participation by persons with developmental disabilities in the same community activities in which nondisabled citizens participate, together with regular contact with nondisabled citizens, and

"(B) the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with nondisabled citizens in their communities."

—Part A, Developmental Disabilities Assistance and Bill of Rights Act

Goals and Visions in the State Council Reports

Virtually all the State Planning Councils highlighted the federal policy goals of independence, productivity, and community integration in their reports. In addition, most of the Councils identified goals and visions for people with developmental disabilities in relation to the various life areas. The following examples of goals and visions defined by the State Councils also summarize the themes identified in their reports in each of the life areas.

Civil Rights

•••All people with developmental disabilities shall have the same rights as individuals without disabilities (*California report*). •••People with disabilities should be entitled to participate fully in every aspect of American life (*Massachusetts report*). •••People with developmental disabilities...have control over their services, thereby directing their own lives (*Guam report*). •••Advocacy must be available and affordable for all citizens who seek to secure and protect their rights (*Florida report*). •••People with disabilities manage their own affairs.... Very few have guardians or representative payees (*Michigan report*). •••People are protected from neglect and abuse...(*Indiana report*).

Education

•••A free and appropriate education should be available to all children in the state...and must be based on the presumption that each child is able to learn and develop (*New Mexico report*). •••Education should be provided in the least restrictive, most integrated environment... (*California report*). •••The primary goal of education for all people must be to prepare individuals for participatory, productive, and contributing roles in society (*Ohio report*). •••Special supports will be available to students with disabilities which are designed to meet their educational needs, including individualized instruction, adaptive equipment, accessible buildings, technological aids, and accessible transportation services (*Texas report*).

Employment and Income

•••Paid jobs in the community will be available to all persons with developmental disabilities who want them (*West Virginia report*). •••Both direct employment-related services (e.g., training, education, pre-vocational, communications skills, etc.) and support services (e.g., transportation, housing, personal care attendants, adaptive devices, etc.) must be readily available (*Massachusetts report*). •••Every person will be afforded the right to have a choice in his or her employment and have adequate information, training, and experience to make an informed choice (*Ohio report*).

•••All people, regardless of the severity of their disability, will choose how to be productive, whether through employment, contributing to their household, or contributing to their community (*Hawaii report*). •••All people are entitled to an income that fosters their highest level of personal independence, enables them to maintain a satisfactory standard of living, and provides for emergencies and old age security (*Indiana report*). •••People with developmental disabilities should have access to income supports which are flexible enough to meet individual needs and are complementary to supports for employment and productivity (*Georgia report*).

Health

•••Everyone has a right to comprehensive, affordable health services provided in a reasonable proximity to one's home.... Persons with disabilities will have the same range of health care choices as other citizens in their community have (*Wisconsin report*). •••Due to prohibitively high health care costs, health insurance is absolutely necessary for all people for protection from financial burden (*California report*). •••An adequate health care system must provide comprehensive services ...(*Georgia report*). •••All persons (with and without disabilities) have access to quality health care.... The quality of patient care is not dependent upon the insurer (*South Carolina report*). •••The generic health care system should provide appropriate acute care services as well as preventive care, diagnostic services, and early intervention to prevent health problems before they become more difficult to treat (*Louisiana report*). •••In the future world where people with disabilities of any kind are no longer discriminated against, providers of mental health services will be willing and able to treat people with various, long-term disabilities (*New Jersey report*).

Housing

•••There will be fewer and smaller segregated facilities for people with developmental disabilities (*West Virginia report*). •••Necessary support services will be provided to families to allow them to maintain their children at home.... There will be alternative, home-like residential settings provided for children who, for one reason or another, cannot live in the natural home (*California report*). •••Adults with developmental disabilities should be in a home of their choosing, have control over the selection of housemates, and the home, whether leased or owned, should be in their own name (*Louisiana report*). •••There should be a sufficient supply of decent, affordable, and barrier-free housing so that people of all income levels and disabilities have access to a home of their choice (Georgia report). •••The [residential service] system guarantees that all staff are both competent and caring (*Rhode Island report*). •••A vision of housing for people with developmental disabilities includes living in the same homes as those without disabilities, with supports to the individual and adaptations to the living environment as needed (*Vermont report*).

Supports to Individuals and Families

•••The vision, then, for people with disabilities who require individual and family supports, is to provide whatever it takes to make their independence, integration, and productivity inside the parameters of society, and outside the institution, possible (*Utah report*). •••There will be an

independent case management system which enables people with disabilities to live successfully in the community by assisting them in accessing different services across the life span (*Texas report*). •••Vision: all persons, including those with mobility impairments, are entitled to the unlimited use of public transportation services which are accessible, affordable, and appropriate (*Massachusetts report*). •••A support system should be developed which is not tied to facilities, and which includes supports which encourage the participation of communities, neighbors, and informal organizations; and supports which are developed and funded based on the needs of individuals (*Tennessee report*).

Summary of State Consumer Surveys

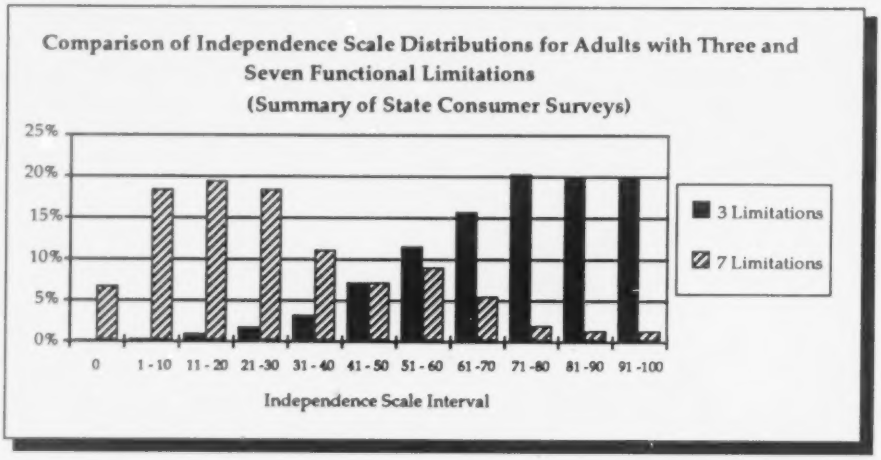
Each Developmental Disabilities Planning Council conducted a survey of consumer satisfaction with services they were currently receiving. In addition, Councils agreed to survey the status of consumers (i.e., people with developmental disabilities) in terms of the goals of independence, productivity, and integration into the community and in terms of current life area status. The Administration on Developmental Disabilities provided support for a national initiative to develop a common survey instrument. Developed by the Temple University Developmental Disabilities Center / University Affiliated Program (UAP) in consultation with State Councils and a scientific advisory panel, the resulting instrument was used in all but five states.

Over 15,000 consumers participated in the surveys. Over 70 percent of the people in the state surveys reported substantial functional limitations in **more than three** life areas. All surveys (except those with very young children) involved the consumer directly; 25 percent of the adults surveyed had no assistance at all in completing the face-to-face interviews, which often lasted two hours or more. In the aggregate, the primary disability of people surveyed was: mental retardation (42 percent), physical disability (41 percent), sensory disability (10 percent), and emotional disability (6 percent).

These proportions and the summary of state consumer survey data presented in the Executive Summary are based on the 13,075 interviews that were sufficiently complete in time to be included in the summary analysis prepared by the Temple University Developmental disabilities Center / UAP for the National Association of Developmental Disabilities Councils.

Summary of State Consumer Survey Findings on Independence, Productivity, and Integration

The common survey instrument included several measures of people's current level of independence, productivity, and community integration. One of the findings highlighted in many State Council reports was that some of the people surveyed with limitations in five, six, and even seven functional areas were reaching significant levels of independence. When people's independence was measured on a scale of 0 to 100, approximately one-fourth of the adults surveyed with seven functional limitations were at the mid-point or higher in independence, as illustrated in the following figure. At the same time, the summary of state consumer survey data also showed that there were substantial numbers of people with only three substantial limitations who were functioning at very low levels of independence.



Data from the summary of state consumer surveys also indicated that some people with as many as seven functional limitations were engaged in productive activities on a regular basis and were well integrated into their communities. Conversely, the summary data indicated that many people with only three functional imitations were at very low levels of productivity and community integration.

Other results from the summary of the state consumer surveys included the following:

- Independence and integration were reported to be important to 75 percent of those surveyed; however, only 26 percent and 38 percent, respectively, saw themselves as independent and integrated.
- People who lived in nursing homes and other institutions were less independent, productive, and integrated than people who lived in community residences.
- People with developmental disabilities had less participation in community living activities and were more apt to feel lonely than people without disabilities.

Summary of the State Consumer Survey Findings in the Life Areas

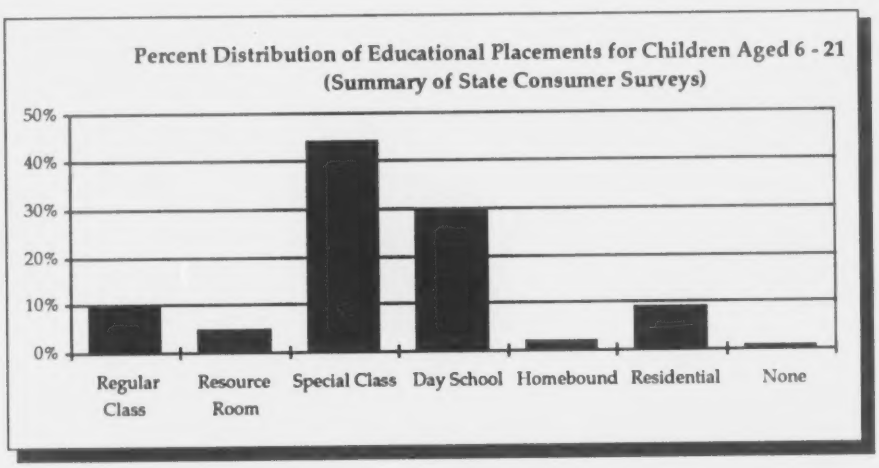
Civil Rights

The Council reports frequently presented consumer survey findings to illustrate concerns regarding the full exercise of civil rights among people with developmental disabilities, as illustrated by the following data from the summary of state consumer surveys:

- 28% of those over 18 years of age voted in the last general election compared with 49% of the general population.
- 39% of those surveyed indicated that they needed legal or protective assistance, but only 27% indicated that they were receiving assistance; therefore, 12% of the population had an unmet need for legal assistance.
- Less than one-fourth of the adults surveyed chose where they were currently living.

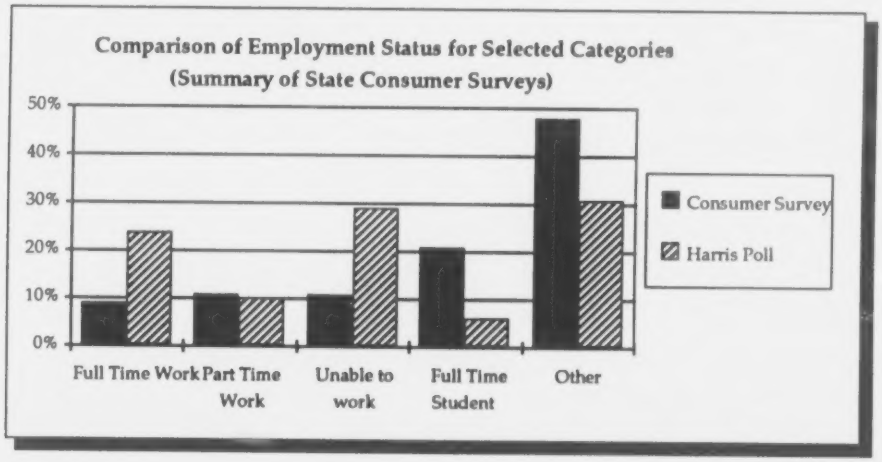
Education

Data from the summary of state consumer surveys indicated that although nearly all children surveyed received education, only 15 percent were receiving their education in integrated classes at least part of the day (i.e., in regular classes or in a combination of integrated classes and resource rooms). Over 40 percent of the children surveyed received their education totally segregated from children without disabilities, and the remainder were being educated in segregated classes in public schools. 73 percent of children birth through age two and 83 percent of children three through age five received either early intervention or preschool programs.



Employment and Income

Some Councils compared the employment experiences of consumers surveyed with the earlier results of a Harris poll of adults with disabilities. These data show that fewer adults with developmental disabilities worked full time; but a larger percentage viewed themselves as able to work. They were much more likely to be enrolled in a full time educational program, probably representing individuals who were in "day habilitation" or pre-vocational programs as well as some young adults still enrolled in public education. These comparisons are illustrated in the following figure from the summary of state consumer surveys.



The hourly wage analysis of the summary of state consumer surveys data showed that those surveyed who had wage earnings were considerably worse off than the general population. A further analysis suggested that the major contributory factor was the sub-minimum wages paid in sheltered employment.

Hourly Wage Study of those People in the Consumer Surveys Aged 16 and Over Working Full or Part Time (Summary of State Consumer Surveys)

- 25% made 49¢ per hour or less
- 50% made $1.28 per hour or less
- 75% made minimum wage ($3.30) or less
- 96% made less than the 1987 US average hourly wage of $9.

<u>Hourly Pay</u>

Mean	$2.52
Median	$1.25
Minimum	$ .01
Maximum	$99.83

Of those surveyed three-fifths were receiving Supplemental Security Income. There was general satisfaction with the programs operated by the Social Security Administration, based on data from the summary of state consumer surveys.

Satisfaction with Financial Assistance Programs
(Summary of State Consumer Surveys)

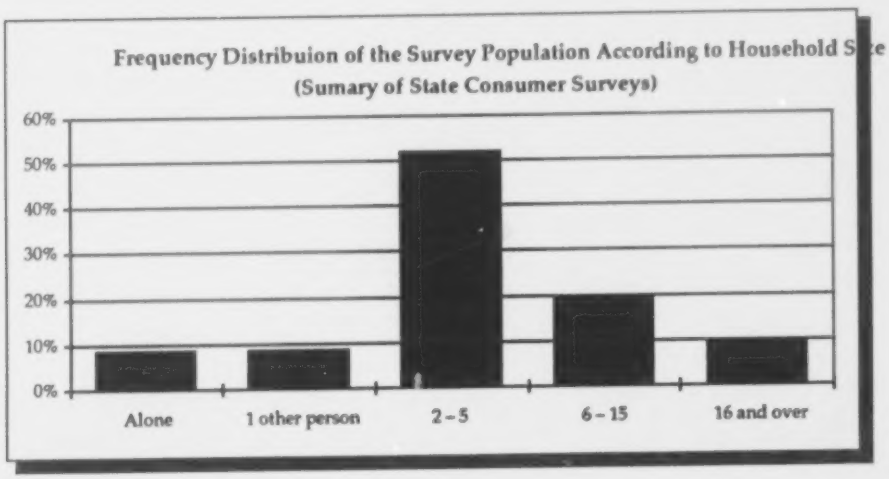
Program	% Receiving	% Using and Dissatisfied
AFDC	10%	31%
SSI	59%	16%
SSDI	22%	14%

Housing

Throughout the reports, the term "housing" was used to refer to where people with developmental disabilities live, including nursing homes and institutions as well as homes in regular neighborhoods. The data from the summary of state consumer surveys indicated that most individuals with developmental disabilities surveyed lived in family-size homes in the community, either independently, with family members, or in family-style arrangements. As illustrated in the following table, nearly one-fourth of the adults surveyed lived in specialized facilities, nursing homes, and institutions, compared to only five percent of children. About one in ten lived with 16 or more people in institutions or institution-like settings.

Where People With Developmental Disabilities Live
(Summary of State Consumer Surveys)

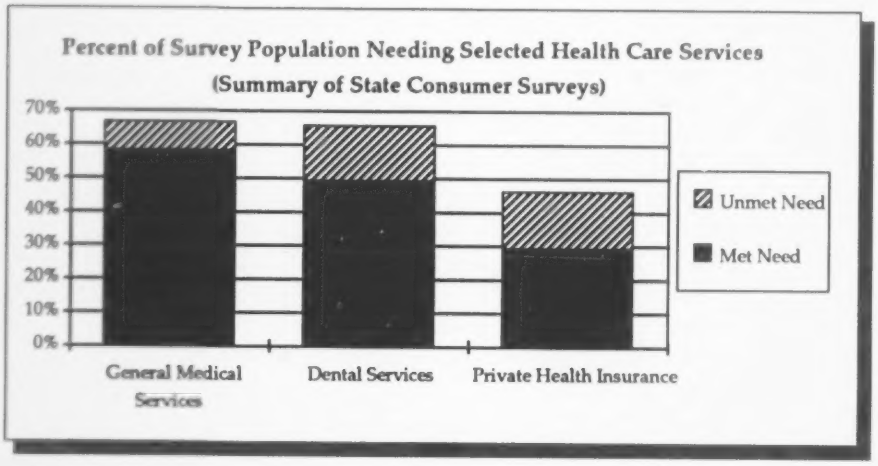
Type	Children	Adults
Home in community	95%	74%
Rooming house	0%	2%
Specialized facility	2%	12%
Nursing home	0%	3%
Institution	3%	9%
Total	100%	100%



A related item on the need for community living assistance showed that 26 percent of all those surveyed needed community living assistance, but only 9 percent were receiving it (for adults only, the figures were approximately 40 percent and 14 percent, respectively); therefore less than one-third of the need for community living support was being met.

Health

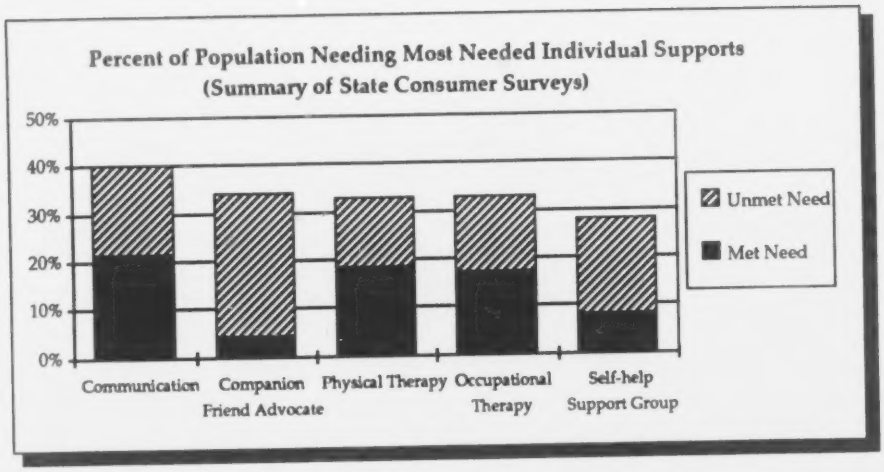
Many Councils included consumer survey findings in relation to health care needs. Health care services were needed by a higher percentage of consumers than other services and supports. Although health care needs were being met to some degree, there were serious deficits in the areas of dental services and private insurance coverage, as illustrated in data from the summary of state consumer surveys.



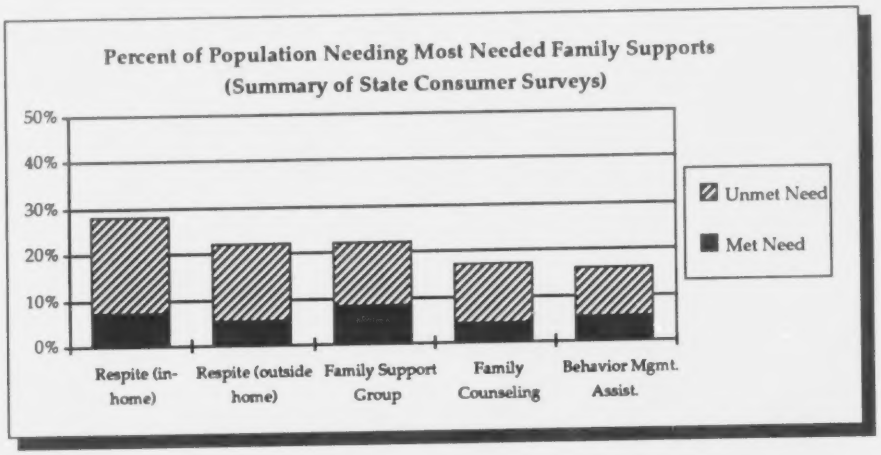
Supports to Individuals and Families

Most Councils included state consumer survey findings in relation to supports. As used in the State Council reports, supports referred to activities and services that assist people with developmental disabilities, or in some cases their family members, in making full use of their opportunities for independence, productivity, and community integration. Supports focus on people's abilities and accomplishments, rather than on their disabilities and dependence. Some of the supports noted in the reports were communication devices, personal assistance, help with money management and community living responsibilities, adaptations of homes and vehicles, and information and referral services.

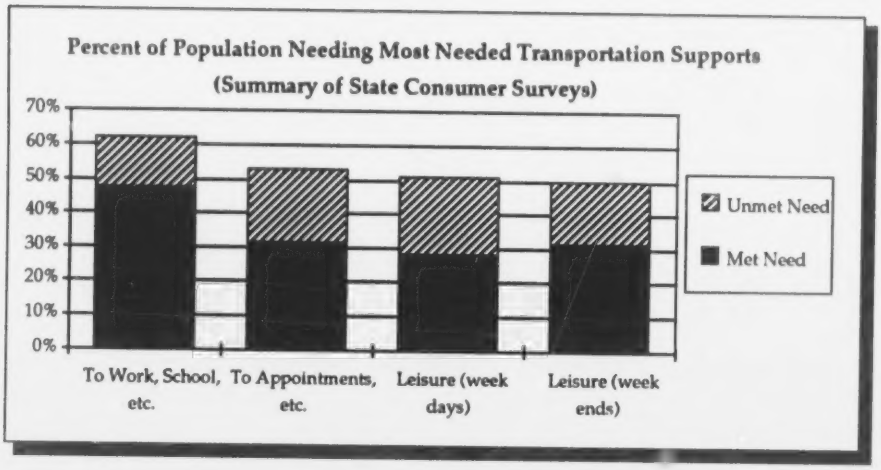
The five most needed individual supports in the summary of state consumer surveys are shown below. Several Councils noted in their reports that next to communication and language support consumers saw the need for a companion or friend-advocate. Although one-half of the need for communication support and physical and occupational therapy was being met, only a small fraction of the need for a friend-advocate and self-help support was being met.



The greatest need for family or caregiver support identified in the consumer surveys was the need for respite care—both in the home and outside the home. As shown in the following figure, this need was being met for only a fraction of those in need. Families needed the support of others who have experienced similar situations, as indicated by the third most needed family support: family support groups. The large size of the unmet need across these five services suggested to many Councils a systemic need to better meet the needs of caregivers. There was also a comparatively high need among those surveyed for family counseling and training that was largely unmet.



Transportation services ranked with the need for medical care as the most needed services of all those contained in the consumer survey. Although two-thirds of the transportation needed to go to work and to attend school and day activities was being met, there were much greater levels of unmet need for transportation to and from appointments, errands, leisure activities, and other personal activities.



The results of these state surveys, collectively the largest survey of people with developmental disabilities ever conducted, will continue to be examined for several years to come. There is a great deal more to be learned from the data about specific age groups, about specific disability groups, and about quality of life issues.

Statements of Consumers and Family Members

The State Planning Council reports contained hundreds of quotes from people with developmental disabilities and their family members. Some reports featured "success stories"; a few examples of these are found in the section on accomplishments. Most, however, were used in the reports to illustrate barriers being encountered, reflecting the emphasis on the identification of barriers in the requirements of P.L. 100–146. Examples from the reports follow.

General

- "Terry will have to move out of the state because there is a minimum wait of two years for head trauma centers. Terry falls in between cracks of existing services." (Ohio parent)

- "There are no programs in the state of Oklahoma which address the needs of families who have a child with autism. If we want our children to enter a school and be properly served, we must send them out of state." (Oklahoma parent)

- "After I graduate, I want to be the first mentally retarded astronaut. If I can't do that, I think I'll be a professional skateboarder!" (Washington consumer)

- "...people with disabilities are not asking for things that other people don't have, but for the same opportunities as all people have.... " (Wisconsin consumer)

Life Areas

Civil Rights/Empowerment

Photo courtesy of Michigan Protection & Advocacy Service

"I am afraid to advocate for myself. When I am assertive I am told I am pushy." (Maine consumer)

"Consumers assigned state guardianship haven't had any contact with their assigned representatives. Those being serviced are not even aware of the name of the person assigned to their case." (New Jersey advocate)

"Section 504 of the Rehabilitation Act has never been enforced. I have not found any real effort to follow through to make public buildings accessible." (Texas consumer)

Education

"Parents no longer have to fight to get in the school door, but they have to fight to get a quality education." (Ohio parent)

"The school system's position is that they'll not provide physical therapy or occupational therapy because they are medically-related and not educationally-related.... I implore lawmakers to modify the language [of the law] to prevent the districts from denying these services to students." (Michigan parent)

"One wish: to go to a regular school and participate in normal activities." (Wisconsin consumer)

Employment and Income

"I work in a workshop and get paid very little money. I get $20 for two weeks of work. I don't think that's right, do you?" (California consumer)

"I want to work for the same reason other people want to work, which is to support myself and to feel like part of the world. Why is that so hard for people to understand?" (Maine consumer)

"Try living on $7,200 a year or $600 a month. Deduct housing, food, clothing, transportation costs, utility bills, heat, medical expenses not covered by Medicaid—like personal care attendants. Could you live on that?" (Michigan spouse)

"Do you really think I like going to that summer camp for the disabled? I'm 40 years old! Hell, if I had the money, I'd go to Hawaii like everyone else." (Washington consumer)

Housing

- "I want to be out of the nursing home and into my own apartment. I have been on a waiting list for six years." (Wisconsin consumer)
- "People with disabilities can get all the independent living training in the world, but it's a total loss if there's no housing for them to move into." (Washington consumer)
- "Well, it seems if they have the money for group homes, why can't they have that for the child at home where he's happy and not take him out of his home surroundings." (Utah parent)
- "Leslie has lived every day of her life in the community. She deserves to continue to live in the community. I want here to have a choice about where she lives. She shouldn't have to go to an institution." (Georgia parent)

Health

- "Casey is eight and is reaching the lifetime cap on his insurance." (Georgia parent)
- "My daughter's...medical bills are around $16,000 a year. There is no way we can pay for her, and the insurance company says that they won't cover her because it's a pre-existing condition. She cannot get off Medicaid and so she can't go to work even if she wants to." (Utah parent)
- "Mental health services have not been adequate and have not met her needs." (Ohio parent)

Individual and Family Supports

- "I shouldn't have to choose between having a wheelchair or a communication system." (Georgia consumer)
- "...I wish I could just meet friends and go to McDonalds and a movie and not have to ask my family to take me." (Michigan consumer)
- "I have not been out with my husband in ten years. I need respite care on a weekly basis or the family will fall apart." (Maine parent)
- "How can a case manager develop good plans and follow through with a caseload of 130?" (Minnesota parent)
- "I ran up a $300 phone bill one month just to find out my child isn't entitled to anything." (New Hampshire parent)

State Council Reports:
Accomplishments and Opportunities

Many State Developmental Disabilities Planning Councils highlighted recent accomplishments that have improved the opportunities of people with developmental disabilities to reach greater independence, productivity, and community integration. Because some reports did not feature such initiatives, many more examples of accomplishments may be identified in the future. The descriptions of accomplishments were used by the State Councils to demonstrate that the vision of independence, productivity, and integration is today a reality for some people with developmental disabilities.

Federal Initiatives

Important federal initiatives were mentioned by the Planning Councils in a variety of areas:

Civil Rights

- Various federal statutes prohibit discrimination based on disabling conditions. The Rehabilitation Act of 1973 (P.L. 93-113, as amended) includes Section 504, the first civil rights legislation to guarantee an equal opportunity for people with disabilities. The Civil Rights of Institutionalized Persons Act (CRIPA) passed in 1980 (P.L. 96-247) empowers the Department of Justice to initiate action to protect the constitutional and federal rights of people in institutions. The Fair Housing Act Amendments (FHAA) of 1988 (P.L. 100-430) address discrimination against people with disabilities in private as well as public housing and rental accommodations.

- The Voting Rights Act of 1965 provides the right to choose a voter assistant. The Voter Accessibility for the Elderly and Handicapped Act (P.L. 98-435) encourages participation and promotes integration by enabling people with disabilities to access polling places.

- The Protection and Advocacy (P&A) program was established by the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103) to pursue legal, administrative and other appropriate remedies to protect the rights of individuals with developmental disabilities under federal and state statutes.

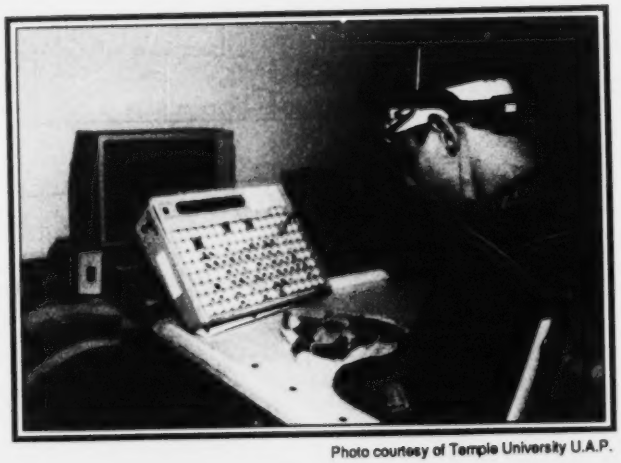


Photo courtesy of Temple University U.A.P.

Education

"The language of the Act makes it clear that a 'zero reject' policy is at the core of the Act [P.L. 94-142] and that no child...is to ever again be subjected to the deplorable state of affairs which existed at the time of the Act's passage, in which millions of handicapped children received inadequate education or none at all." (875 F. 2nd, 954, 1st Circuit, 1989). (U.S. First Circuit Court of Appeals)

Employment and Income

★ Several Councils commended the federal Rehabilitation Service Administration for its systems change grants, which were seen as important in the progress toward the goal of productivity in their state.

Housing

★ Teresa shares her home with two friends and receives training, case management and other support services from staff of the regional [state facility]. She reported that her present home is one of the best places she's ever lived. "It's big, for one thing. We've got our own washer and dryer. We don't have to go out to the laundromat. HUD pays for part of the rent and we pay for the rest of it. If it weren't for HUD, we wouldn't be able to live here." (West Virginia report)

Photo courtesy of University of Georgia U.A.P.

Supports

★ Although the majority of Councils were concerned about the need for Medicaid reforms, some identified the Home and Community Based Services waivers as a significant step in the right direction in providing access to individual and family supports.

State and Local Initiatives

Many State Council reports highlighted recent Council and state government actions that have promoted increased independence, productivity, and community integration of people with developmental disabilities. State programs and initiatives in education were frequently cited in the reports, such as the use of "mainstreaming specialists" and Minnesota's mentor/friendship program in the schools. Other Councils pointed out innovative transition programs. Several reports featured the involvement of the private sector in the employment of people with developmental disabilities, including major employers such as McDonalds, Boeing, IBM, and the Marriott Corporation, as well as smaller employers at the local level.

A few State Councils highlighted initiatives in the health area, such as rural outreach programs and services through the children with Special Health Care Needs Program. Some reports cited beginning efforts to address barriers to private health insurance coverage. In housing, many of the reports described state initiatives to reduce the use of their large public institutions, especially for children with developmental disabilities. State and local supported living initiatives also were featured.

Many Councils described initiatives in supporting individuals and families, such as the provision of personal care attendant services, assistive technological aids and devices, parent-to-parent networks, and family cash assistance programs. Councils mentioned the importance of information and coordination and a few examples of model information and referral and case management programs were featured.

Many accomplishments were featured in the State Council reports that have minimal government involvement. These efforts of the private sector, private citizens, and local communities to support people with

developmental disabilities in communities were seen by State Planning Councils as some of the best opportunities for them to achieve the goals of maximum independence, productivity, and integration into the community.

Civil Rights

- Several states have enacted legislation patterned after the Rehabilitation Act. These laws prohibit discrimination in programs or activities conducted by or funded through state funds.

- Individuals in many states have become active in the self-advocacy movement (e.g., People First), providing a major forum for people with disabilities to problem solve, vent common frustrations and coalesce around major life issues of critical importance such as housing, employment, transportation, societal perceptions and portrayals of people with disabilities.

- Many states discussed their quality assurance activities in regard to protecting people from harm. In Utah, for example, a volunteer monitoring committee has been established, where volunteers are trained to monitor residential facilities, both congregate and community based. Homes are visited three times; once announced, twice unannounced.

Education

- In New Hampshire several school districts have developed a new role for special education teachers called "Mainstreaming Specialist," "Integration Specialist," or "Consulting Teacher." These individuals act as "consultants, team-teachers, service-coordinators, and in other flexible roles to support the inclusion of students with disabilities in regular educational environments." (New Hampshire report)

- California has a seven year old "WorkAbility" project that has served more than 43,000 students. This project represents the cooperative efforts of the state departments of education, rehabilitation, and employment development to provide assessment, employment preparation and training, community work experience, and support services. In recent years the project has been extended to the community college level. (California report)

Employment and Income

- The Job Accommodation Network was cited by several reports as the kind of private sector initiative that made the work place accessible. This network is totally managed and operated by employers who provide technical assistance to other employers. Their advice is based upon approaches to accommodating the work place that have been used successfully by businesses.

- In October of 1987, the Governor of Colorado signed an executive order promoting state agency employment of persons with disabilities. From November 1987 until April of 1989, 78 of the 142 people with disabilities hired by the state were hired under the provisions of the executive order. (Colorado report)

Photo courtesy of the Oklahoma Planning Council for Developmental Disabilities

★ "The most tangible benefit is that they build quality products just like everybody else does." (Dave Jay, Director of Production, Physio-Control, a firm manufacturing bio-medical equipment that has hired 15 workers with disabilities—quoted in the Washington report)

Housing

★ At the beginning of October 1989, the population of [the state institution] was 95 residents. The population has steadily declined for more than a decade as admissions have ceased and efforts to achieve community placements have been a top priority within the Division of Mental Health and Developmental Services. During the past two years the population has declined by about 30 residents per year and the number of community placements has consistently exceeded projections. (New Hampshire report)

Photo courtesy of A.J. Pappanikou Center on Special Education and Rehabilitation, A. UAP University of Connecticut

★ In a recent deinstitutionalization effort, an employee of the Utah State Training School chose to become a private provider for three women who had resided in the training school for 17, 23, and 31 years respectively. As a private provider, she took these women she had worked with in the institution and helped them integrate into a community setting. Early on she observed that Mary had almost never spoken in the ten years she had known her, but since "coming home" (Mary's description) she has become a regular "chatter box." The provider assumed while at the training school that these women must have dressed uncaringly because of the severity of their disabilities. But in the community each of the women had very definite ideas about how she wanted to dress: one loved purple and lace, another chose levis and sweaters, and another sports clothes like "sweats." She said, "I would like to take credit for teaching them all of the new things they're doing, but I can't. I really haven't done anything but give them a chance...they just haven't had a chance before." (Utah Report)

❝ I lived at Dixon Developmental Center for 28 years...now I have moved to my own apartment.... I signed my own lease, pay my own bills, and for the first time I can stay home without staff. This is the best place I have lived so far. I like my roommates, and this is our place." (Illinois consumer)

Health

★ Outreach to rural areas was featured in the Utah report, which described the "travel clinics" of the state's Handicapped Children's Services and Maternal and Child Health (MCH) programs. The MCH outreach includes the expertise of its high risk pregnancy program. The report noted that the outreach philosophy reflected in these activities is found throughout the programs administered by the state public health agency. (Utah report)

★ Loyola School of Dentistry's Division of Preventive Dentistry and Community Health has made a commitment to working with their dental students so that they have a wide variety of experiences with people with disabilities during their educational training. (Illinois report)

★ The Wisconsin Department of Health and Social Services and the Department of Public Instruction have entered into a cooperative agreement with a pilot county in an effort to address several critical issues for children with emotional disturbances. The Robert Wood Johnson Foundation is providing Wisconsin with a one-year grant of $100,000 to support the development of a coordinated array of community treatment and support programs for youth with serious emotional disabilities. This effort is indicative of a relatively new kind of cooperative activity between the public and private sectors. (Wisconsin report)

Individual and Family Supports

★ The Pennsylvania Attendant Care program utilizes a combination of state funds and the federal Social Services Block Grant, as well as consumer payments on a sliding scale. The program is available across the state and is currently reaching 1,013 adults with physical disabilities with an average of 40 hours per person per week. A key aspect of the program is its emphasis on consumer control. (Pennsylvania report)

★ In Arkansas two pilot family cash assistance programs were initiated in 1988. The pilots are funded through [the state developmental disabilities service agency], with a current funding level of $206,000 for about 40 families; about 77 families are on a waiting list. Cash may be used to purchase nearly any good or service that is deemed relevant to the family's circumstances and that is not obtainable from other funding sources. (Arkansas report)

★ The significance of supports to communities in relation to goals for people with developmental disabilities was recognized in many of the state reports. Some highlighted activities designed to involve community members directly in the lives of their fellow citizens with disabilities. For example, the Colorado report described a project funded by the state Developmental Disabilities Council in 1989 to develop "Circles of Friends" in five communities in the state. As described in the report, the purpose of these programs is to organize communities in ways that connect people with developmental disabilities with other community members, foster long-term relationships, and develop assistance to consumers in their self-advocacy and full participation in community life. It is hoped that these interactions also will promote changes in public attitudes toward people with developmental disabilities. (Colorado report)

State Council Reports: Critical Issues and Barriers

There were service and support areas around which there was State Developmental Disabilities Planning Council consensus, such as the need for individual and family supports, for supported employment, and for community living alternatives. Although there were common issues raised by the State Councils based upon a shared understanding and commitment to the goals of independence, productivity, and integration into the community, there were also major differences. In large part the differences seemed to reflect differences among the states in the evolution of their community service systems. For example, a few states were reported to have virtually completed the deinstitutionalization process while others have barely begun. Some states have extensive case management programs and are primarily concerned about quality, while a few states have no case management programs and are concerned about their availability.

Several issues raised by the State Planning Councils can be generalized as fundamental or "cross-cutting" in that they cut across life areas and program areas. They can be summarized as follows:

- **People with developmental disabilities too often lack the basics of American life: a good job, good and caring friends and family, and a home (as opposed to a residence or "placement").**
- **Services and supports too often fail to promote the goals of independence, productivity, and integration into the community for people with developmental disabilities.**
- **Programs and services too often are inflexible, forcing people with developmental disabilities to conform to the programs and services regardless of individual needs and preferences.**
- **Diagnostic labels, age, cultural background, and severity of disability too often are used to "pigeon-hole" people with disabilities.**
- **Funding too often is allocated to programs and services rather than individuals.**
- **People with developmental disabilities too often are discriminated against and their rights as human beings are abridged.**
- **People with developmental disabilities, their family, and friends often lack the information to make informed choices.**

The issues surrounding the realization of the visions and goals that the State Councils put forward for people with developmental disabilities fell primarily into only a few categories. The State Council reports provided detailed descriptions of the unmet needs of people with developmental disabilities generally in terms of the **availability** of particular supports, services, or programs. In some cases, services were unavailable because of eligibility barriers.

Occasionally, Councils reported that services were available, but that they were not **accessible** to people with developmental disabilities because of barriers such as physical inaccessibility, discriminatory practices, high costs, the lack of financial resources by the person with a developmental disability, and lack of information or outreach.

State Councils pointed out many situations wherein services or programs had a **focus** that did not meet the goals of independence, productivity, and integration for people with developmental disabilities. Major issues also were expressed about the **quality** of services.

The last major type of issue had to do with **consumer control.** Many State Councils felt that people with developmental disabilities frequently did not have enough control over their lives and the services that were important to them.

Availability

In each of the life areas Councils reported that there were significant gaps in services. Generally, these were of two types. The first gap had to do with the fact that particular services, supports, or programs **did not exist**, there were **not enough** services or programs, or there was a **lack of service or support options**. One indicator of insufficient services noted by many Councils was the presence of a waiting list. The second kind of gap had to do with **population exclusion**. Throughout the state reports, there were examples of people with developmental disabilities who were excluded from service because their particular disability did not fit into a particular eligibility category. This was true across all the life areas, particularly for those services operated by state agencies designated to serve people with mental retardation; however, it was also found by some Councils that people who were technically qualified to receive services were turned away or put on waiting lists.

Several barriers that limited availability of services and supports were mentioned by the State Councils. Restricted availability of service was generally traced to a lack of resources within state or federal programs. Although a lack of financial resources was most commonly mentioned, there were also serious concerns raised by a majority of Councils regarding the lack of human resources, in the form of adequate numbers of trained people to provide services. Several State Councils mentioned the barrier of ignorance and public attitudes about the needs and capabilities of people with developmental disabilities on the part of the general public, elected and appointed government officials, service providers, and even people with developmental disabilities, their families and friends. Other barriers mentioned were the lack of strong state and federal leadership, weak information systems, and the barriers of geography (e.g., rural areas). At another level some State Councils saw the weakness of their state economy as a barrier to developing the fiscal resources needed.

The specific gaps in services reported by the State Councils varied from state to state; the most common availability issues were in relation to individual and family supports, "real jobs for real pay", social and recreational opportunities, and homes in the community. The following list illustrates the primary programs, services, and supports identified in the State Council reports as insufficiently available. It should be remembered that these were not issues in every state and that the nature of the availability "problem" was unique to each state.

Civil Rights

- Affordable legal services
- Guardianship
- Protection and advocacy services

Education

- Adult and post-secondary education
- Assistance/supports to personnel and non-disabled students to support full integration
- Infants, toddler, preschool education and early intervention; Head Start—especially for children with severe disabilities
- Related services and supports
- Vocational education

Employment and Income

- Employment supports—especially long-term; job accommodations, technology in the workplace
- Fair wages; fringe benefits; real job opportunities, opportunities for advancement
- Income subsidies—lack of information and outreach on work incentive programs
- Supports and incentives for private employers

Health

- Community mental health services—counseling and long-term support
- Comprehensive health insurance coverage—Medicare, Medicaid, private
- Eligibility for health insurance—private, some Medicaid and Medicare
- Providers who accept Medicaid

Housing

- Affordable housing units
- Community living alternatives and support services
- Home based services for children with high medical needs

Individual and Family Supports

- Family supports to maintain household—especially respite care
- Individual supports: occupational, physical, speech and language therapies; personal assistance services; technology — adaptive equipment, assistive devices
- Information and referral
- Integrated programs for older individuals with developmental disabilities
- Recreation and leisure time supports, integrated activities
- Transportation—especially in rural areas

Accessibility

Many Councils reported that people with developmental disabilities were unable to have their needs met because, even when services and supports were available, they were inaccessible. Although the reason in many cases was a lack of resources to serve all who needed the service (availability, see above), some services were physically inaccessible. Again, some barriers were geographic, but more often they had to do with the lack of supports and assistive devices. Other barriers identified by Councils were ignorance or attitude. Opportunities to participate in services and other communities were also thwarted by isolation and segregation, often associated with people living in institutions and nursing homes. Another barrier to accessing programs, services, and supports mentioned frequently in the reports was that consumers and family members were unaware of services. As with availability, lack of commitment and leadership was also reported to be a barrier in some states. Issues of accessibility included:

Civil Rights

- Discrimination on the basis of disability
- Enforcement of accessibility rights and protections; voting assistance, polling place accessibility

Education

- Fully integrated educational services—all ages, including adult and post-secondary education

Employment and Income

- Job opportunities for people who require extensive supports or accommodations in the workplace

Housing

- Affordable housing that is also accessible
- Community living and participation

Individual and Family Supports

- Accessible transportation especially for people with physical disabilities; transportation for people in more rural areas
- Interpreters and TDD systems

Focus

The State Councils frequently took issue with the focus or direction of programs and services. As required by P.L. 100–146, the Councils were to analyze programs in terms of how well they were directed to the goals of independence, productivity, and integration into the community for people with developmental disabilities; therefore, the reports raised many issues regarding the effectiveness of programs and services to achieve these outcomes.

State Councils found many programs and services lacking in relation to the attainment of these goals. The major reasons or barriers cited in the reports included: program missions or goals out of line with the promotion of independence, productivity, and community integration; legislative restrictions; a lack of or misdirected leadership by policymakers regarding the capabilities of people with developmental disabilities; low expectations regarding the capabilities of people with developmental disabilities; and other or vested interests incompatible with those of the consumers. Programs that were mentioned by State Councils as "missing the mark" in relation to independence, productivity, and community integration included:

Civil Rights

- Guardianship—used inappropriately; too restrictive

Education

- Segregated education programs
- Special education—not career and life goal focused
- Transition to employment, adult services—poor coordination

Employment and Income

- Income assistance and subsidy programs—contain disincentives to employment; too low to promote independence
- Medicaid—disincentives to employment; weak coverage of employment-related supports
- Segregated/sheltered rather than integrated/supported employment
- Vocational rehabilitation—not focused on employment / job placement; long-term support guarantee requirement

Housing

- General funding bias toward congregate housing and economies of scale in the provision of housing support
- Inappropriate nursing home placements
- Medicaid Intermediate Care Facility/MR facilities—too restrictive, not "home-like", segregated

Health

- Restrictions on Medicaid and other insurance programs—payment for supports, therapies

Individual and Family Supports

- Restrictions on how supports can be used
- Segregated recreation and leisure opportunities

Quality

Photo courtesy of U.A.P. Cincinnati Center for Developmental Disabilities

Even when services were available and properly focused, there was yet another set of issues raised by the State Councils: services were of **unsatisfactory quality;** they did not achieve the results that were desired. Councils also identified some programs that failed to meet the over-arching expectation that programs and services should meet the **individual** needs of people with developmental disabilities. In some cases Councils related poor quality to poorly trained and motivated staff. Councils identified personnel issues across the life areas, including early and school-age education, supported employment, health care, residential services, case management, personal assistance, and transportation. In others the reports identified weaknesses in quality assurance procedures. Some Councils saw a lack of accountability for services and programs provided with public funds, including lack of information or data on how service participants were doing. Other barriers identified by Councils included the lack of fiscal and human resources. In addition to personnel issues, quality concerns were raised in the following areas:

Civil Rights

- Monitoring of guardianship programs

Education

- High dropout rates
- Special education individual planning process - insufficient attention to individual needs

Employment and Income

- Income supports—demeaning application process

Housing

- Institutions, congregate living programs, nursing homes—lack of individualized programs
- Quality assurance programs—weaknesses in monitoring; not based on independence, productivity, and integration; compliance in institutions resulting in less resources for community living arrangements

Individual and Family Supports

- Case management programs—caseloads too high, conflicts of interest
- Transportation programs—poor service

Consumer Control

Nearly all State Councils raised the issue of consumers' lack of control or independence in making decisions about their programs, services, and supports, and, most importantly, about their futures. For children, Councils raised the issue of family control and empowerment. The lack of consumer control was seen by the State Planning Councils as having a deleterious effect on the overall quality of life for people with developmental disabilities. The reports pointed out several areas where consumer influence and control were lacking, including the planning and monitoring of services, supports, and programs as well as the choice among services. Many barriers to increased consumer control and choices were identified by the Councils. Low expectations for people with developmental disabilities on the part of some policymakers and family members was seen as a key barrier that was shared with many providers. A related barrier was professionals' fears of losing control over services. Several reports also noted that consumers often lacked the information and skills to control services and other key events in their lives. Areas where a lack of consumer control was reported by Councils included:

Civil Rights

- Options for limited guardianships
- Oversight of civil and legal rights

Education

- Educational programs and services—participation in individual education plans

Employment and Income

- Employment opportunities/career choices

Housing

- Housing and living situation—type, location, furnishings, housemates
- Planning, monitoring

Individual and Family Supports

- Personal assistance services
- Planning and monitoring—individual and family supports; transportation

Photo courtesy of HDS Photo Library

State Council Reports: People who are Unserved or Underserved

The State Planning Councils were required by P.L. 100-146 to identify people with developmental disabilities who are currently unserved or underserved in the state or territory. Although every Council report identified at least one population subgroup as unserved or underserved, it should be noted that the one group named in all reports was people with developmental disabilities in general. Others identified, in descending order of frequency, were as follows:

- Individuals with severe, multiple or very challenging disabilities
- People with physical disabilities, such as cerebral palsy, head injury, epilepsy
- People with mental health needs, including people with a dual diagnosis omental illness and another developmental disability

- Individuals with mental retardation or other cognitive limitations
- People with sensory disabilities
- People with low incidence disabilities
- People with autism

Others found by Councils to be unserved or underserved included residents of rural areas, people with low incomes, members of racial or ethnic minority groups, young adults who "age out" of the public school system, and older individuals with developmental disabilities.

Councils identified many areas of services and supports where people with developmental disabilities were unserved or underserved, as noted in the summary of State Council report findings on critical issues and barriers. In addition, several Councils identified some people with developmental disabilities as being **inappropriately** served in relation to the promotion of independence, productivity and community integration. The groups identified as inappropriately served were primarily those in segregated settings, including institutional living arrangements, sheltered workshops, and segregated learning environments.

State Council Reports: Recommendations

The recommendations found in the State Council reports paralleled closely their findings on critical issues and barriers. The primary recommendation regarding insufficient availability of programs, services and supports was that they **be made more available** and **more accessible**. Similarly, Councils recommended a **change in focus** of programs and services that were limiting people's opportunities for independence, productivity, and community integration; an **improvement in quality** and in quality assurance mechanisms; and initiatives to **empower consumers** and give them more choice and control over their lives. Although there were many recommendations to increase program scope or to add services in some areas, the one common exception was in relation to large congregate facilities, which were recommended for reduction in utilization by virtually every Council. Overall, recommendations tended to be "action oriented"; although found in some reports, there were relatively few recommendations that were limited to "further study" of the issues.

The following represents a synopsis of the major recommendations from the Developmental Disabilities Planning Councils of the 55 states and territories. Those recommendations that were directed primarily at the federal level are preceded by a miniature map of the country:

Availability/Accessibility

The State Council reports called for increased availability of services in order to serve additional people with developmental disabilities, expand services to those already receiving them, and expand the service options available. The expansion or redirection of resources was the strategy most frequently recommended by Councils to increase availability and access. Some Councils recommended the removal of eligibility barriers, including some based on income as well as some on type or severity of disability. Legislation, public education, and education of policymakers were seen by some Councils as ways to counteract some aspects of discrimination.

A strong recommendation was made in 19 reports that **the Americans With Disabilities Act be passed and signed into law**. The states saw this as a major civil rights initiative that was necessary for people with developmental disabilities in their states. There were also recommendations that state civil rights, guardianship, and accessibility statutes be brought into line with federal policy.

The programs and services listed below summarize the various recommendations made by Councils in relation to increased access and availability for people with developmental disabilities. The basic recommendation in the reports for each of these was that they be made more available and/or that access to them be improved for people with developmental disabilities. As with the summary of critical issues and barriers, it should be noted that the specific recommendations made by the State Council reports varied regarding their focus and the strategies that were considered appropriate within the individual context of the state or territory.

Civil Rights

Enact Americans With Disabilities Act.

- Enact and enforce state protections.
- Guardianship—increase availability of appropriate options

Education

Education of the Handicapped Act (P.L. 94–142)—require full coverage of ages 0 through 21; increase federal support

- Educational placement options, related services, vocational education, post-secondary, and adult education
- Integrated early childhood education
- Transitional services—between pre-school and elementary school and between high school and employment; adult services

Photo courtesy of HDS Photo Library

Employment and Income

Employment supports—more resources / less restrictions for long-term supports

- Employment supports—more resources, increased access for people with physical disabilities, severe disabilities; employer training, technical assistance

Improve Supplemental Security Income eligibility determination for children with developmental disabilities.

- State supplemental payment programs—create, expand eligibility.

Health

Maternal and Child Health block grant—consider requiring minimum portion to be used for the Children with Special Health Care Needs program.

- Medicaid—expand eligibility at the state level; reduce disincentives for provider participation.

Medicare—expand eligibility to people during the first two years of Social Security Disability Insurance benefits.

Private health insurance—consider increased federal regulation.

- Private health insurance—expand regulation, access through state actions.

Housing

- Community housing options; community living supports

Low income housing that also is accessible

Individual and Family Support

- Family supports

Federally funded aging programs—increased access for people with developmental disabilities

- Individual supports—technology, personal assistance, transportation
- Information and referral programs
- Informal supports ("circles of friends"); recreation

Focus

The State Councils recommended changing the focus of a wide range of federal and state programs to better serve people with developmental disabilities in achieving the goals of independence, productivity, and integration into the community. These changes were recommended across all the life areas. Two areas that were seen as most critical by Councils were housing and employment.

Civil Rights

- Guardianship—use less restrictive options
- Involve consumers in planning, policymaking, and oversight
- Promote self advocacy

Education

Education of All Handicapped Act—to promote full social and educational integration of all students; consider mandating individual transition plans; increase federal funding

- Educational transition and life planning
- Special education curriculum and placement options

Employment and Income

- Adult vocational service system—focus on private sector employment for people with severe and persistent disabilities; access to fair wages and employee benefits

Expand Medicaid coverage of supports to employment.

Federal work incentives—expanded access and scope of programs

Rehabilitation Services Act—expand supported employment provisions.

SSI, SSDI, AFDC benefit levels—increase to promote independence.

Health

Medicaid—remove bias toward services provided in hospitals, institutions.

Housing

- Redirect resources from large congregate facilities to community living, supported housing models.
- Promote opportunities for home ownership, holding lease in own name.

Individual and Family Supports

Reform Medicaid in ways that expand the use of Medicaid for supports to individuals; refocus on individuals rather than facilities.

Quality

State Council reports contained many recommendations to improve the quality of services and supports. Often these had to do with improved quality assurance efforts on the part of government and providers, such as increased public accountability. In other cases improvement in quality had to do with making greater and better investments in the people who provide services and supports, including ongoing opportunities for in-service training and consultation. Some Council recommendations focused on the need for more individualized services. The following areas summarize the State Council recommendations for improved quality of programs and services:

Civil Rights

Enforcement of existing civil rights statutes

Federal, state, and local program monitoring activities.

- State civil rights law enforcement

Education

- Life and transitional planning and curricula in education
- Post-education tracking to ensure that services were effective
- Special education and related services — personnel preparation
- Vocational education—involve business community.

Employment and Income

- Individual vocational plans
- Vocational services organizations—personnel preparation
- Training, technical assistance, and support to employers

Health

- Health care provider education and training in serving people with developmental disabilities

Housing

- Community living programs—personnel training and qualifications, program monitoring

Consider federal board and care standards.

- Meet institutionalized quality standards, nursing home reform requirements without taking resources away from community programs.

Individual and Family Supports

- Case management—independent of providers, service system; personnel preparation, reduced caseloads
- Individual supports—personnel preparation
- Transportation—personnel preparation, responsiveness

Consumer Control

Increased consumer control over services, supports, and individual choices, as well as family empowerment in relation to children with developmental disabilities was recommended by nearly all of the State Councils. By and large, the Council reports recognized this requirement if the goals of independence, productivity, and integration into the community were ever to become a reality. Cutting across the areas listed below were State Council recommendations that people with developmental disabilities be active participants on the boards, commissions, and committees that plan and monitor the programs that affect them.

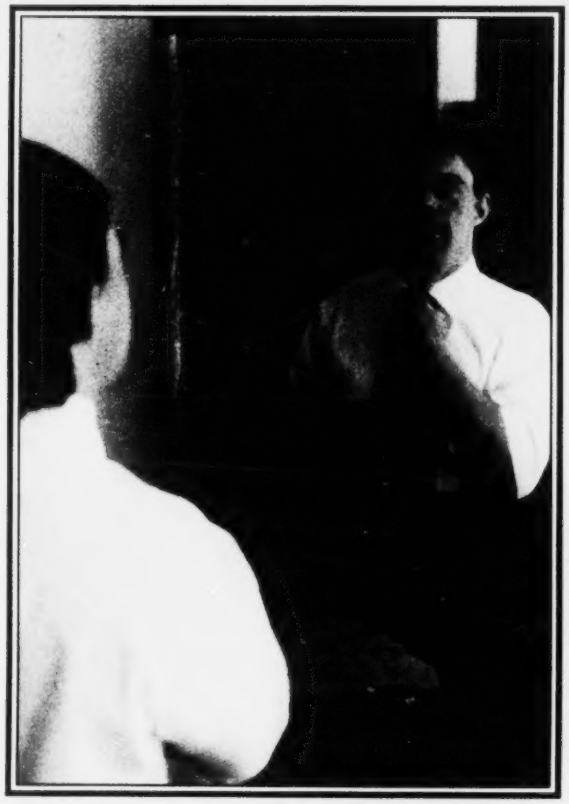


Photo courtesy of A.J. Pappanikou Center on Special Education and Rehabilitation, A. UAP University of Connecticut

Civil Rights

- Civil and other legal rights
- Life planning and major program decisions

Education

- Educational decision making

Employment and Income

- Career choices

Health

- Health and medical care choices

Housing

- Community living choices

Individual and Community Support

- Family supports and services
- Individual supports and services

Cross-cutting Principles

The specific recommendations of the State Planning Councils reflected the differences among service systems and state priorities. At the same time, nearly all of the reports contained statements of principles that were the overarching themes for the Councils' recommendations. There was great consistency among the State Councils in the principles and cross-cutting recommendations that were articulated. These may be summarized as follows:

- **Services and supports must focus on the goals of independence, productivity, and integration into the community for people with developmental disabilities.**
- **People with developmental disabilities need to be supported to be as independent, productive, and integrated as possible; they should not simply be "served."**
- **Programs must be made flexible to meet individual needs; they should not be based on diagnostic labels.**
- **People should not be excluded from programs and services that meet their needs because of a particular diagnostic label or because of a particular disability.**
- **Funding should follow the individual with a developmental disability.**
- **The rights and responsibilities of people with developmental disabilities must be scrupulously fostered and adhered to . They should not be discriminated against on the basis of their disability.**
- **A strong information system must be maintained on the status of people with developmental disabilities.**

State Council Recommendations for State Agency Responsibility

Under the requirements of P.L. 100–146, one aspect of State Councils' reviews of state agency administered programs was an assessment of barriers to services in relation to the assignment of responsibilities among state agencies. The majority of Councils concluded that some of the barriers to people who are unserved or underserved were related to the assignment of responsibilities among state agencies. Findings were mixed between absence of state agency responsibility for particular populations (e.g., no agency with specific responsibility for people with physical disabilities) and use by state agencies of a categorical (e.g., presence of mental retardation) rather than a functional definition of eligibility, such as the federal definition of developmental disabilities.

Virtually all State Council reports included several recommendations regarding the assignment of state agency responsibilities to improve access to services. These recommendations varied from general assignments of responsibility to designations of specific authority for individual services or populations. The population group mentioned most frequently in these recommendations was people with developmental disabilities other than mental retardation. Others noted in the reports were people with dual diagnosis of mental illness and other developmental disabilities, people with multiple disabilities or severe health care needs, people with head injuries, and people in various age groups. There were also many Council recommendations for state agency responsibilities in relation to people with developmental disabilities in general. About one-third of the Councils recommended that decisions on specific assignments of responsibility for the full range of people meeting the federal definition of developmental disabilities be deferred until a more thorough review of the findings of their reports could be made.

From a different perspective, State Councils indicated that many services needed were not necessarily disability specific. For example, a housing agency might serve people of different disabilities, incomes, and ages. Looking at the state in this way Minnesota recommended, "...that each existing agency work to ensure the needs of all people who are unserved and underserved are met. There is no single agency that can accomplish this mission alone."

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The Developmental Disability Planning Councils of the states and territories have presented impressive descriptions of the progress some people with developmental disabilities have made toward the goals of independence, productivity and full community integration. At the same time, the Council reports indicated that these goals have not yet been realized for many other individuals with developmental disabilities, and that there are many barriers to their opportunities for independence, productivity and integration.

The State Council reports contain a wealth of recommendations on ways to reduce these barriers, including Council implementation plans and specific strategies to improve the effectiveness of programs and policies; related strategies can be found in the State Developmental Disability Two-Year Plans recently submitted by the Councils to the Administration on Developmental Disabilities. Collectively, the 1990 reports prepared by the State Planning Councils provide the basis for creating new opportunities for people with developmental disabilities. The information from these reports will serve as a major resource at all levels in the review of current programs and policies and in the development of new initiatives to promote full citizenship for people with developmental disabilities.